



Living with tinnitus and the health care journey: An interpretative phenomenological analysis

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Objectives. Tinnitus is a very common experience, and although usually mild, in a significant proportion of people, it is intrusive, persistent, and disabling. This paper explores the lived experience of chronic disabling tinnitus, with the aim of understanding how distress and chronicity occur, and what might help to reduce this.

Design. Nine individuals were interviewed 6 months after completing mindfulness-based cognitive therapy (MBCT) as part of a randomized controlled trial. The results reported here focus on their experiences of tinnitus before receiving MBCT.

Methods. Data were collected through semi-structured, face-to-face interviews with a clinical psychologist, and an interpretative phenomenological analysis approach was used.

Results. Two supraordinate themes emerged. ‘Living with tinnitus’ describes a range of significant and profound life changes that result from the condition. Tinnitus can be a life-altering condition affecting thoughts, emotions, attention, behaviour, and the social world. ‘The health care journey’ shows how chronic distress was intensified by unhelpful health communications and alleviated by helpful consultations.

Conclusions. Tinnitus is a biopsychosocial condition, and associated distress is affected by cognitive, behavioural, attentional, and social factors. The individuals’ initial reactions to tinnitus interact with the responses of others, including health care professionals. The burden of tinnitus could be reduced by developing early interventions that offer clear, helpful, and realistic information about tinnitus and appropriate treatments.

Statement of contribution

What is already known on this subject?

- Tinnitus is the experience of an internal sound without an external sound source.
- It can be troubling, disabling, and chronic and usually has no clear medical cause or medical treatment, but psychological interventions are promising.
- Cognitive, behavioural, and attentional factors play a role in distress and therapeutic outcome.
- Clinical encounters are improved by aligning patient and clinician and sharing decision-making.

What does this study add?

- It is the first in-depth study exploring how tinnitus distress and health care systems interact.
- It shows how a biopsychosocial approach to tinnitus may reduce tinnitus burden more effectively than a biomedical, diagnostic-focused approach.
- It indicates how effective early health care information could be used to reduce chronic tinnitus distress.

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Tinnitus is the internal experience of sound (often a ringing or buzzing) in the absence of an external sound source. It is one of the most common persistent physical symptoms reported by humankind affecting up to 30% of the population at any time (McCormack, Edmondson-Jones, Somerset, & Hall, 2016). Rates of associated suffering are lower, and epidemiological studies have found that 5% of the population report mild to moderate disturbance resulting from tinnitus, with 0.5–2% reporting severe disturbance (Fuji *et al.*, 2011; Henry, Dennis, & Schechter, 2005). In 2005, the RNID estimated that 13 million patients in the United States and Western Europe sought medical attention due to tinnitus (Vio & Holme, 2005).

When severely disturbing, tinnitus can significantly affect emotional well-being, with elevated rates of anxiety and depression (Goebel & Floetzinger, 2008), stress (Mazurek, Szczepek, & Hebert, 2015), insomnia (Schecklmann *et al.*, 2015), concentration difficulties, and reduced quality of life and functioning (Baguley, Andersson, McFerran, & McKenna, 2013). Tinnitus onset varies, often occurring after stressful life events or auditory changes. Subjective tinnitus loudness is associated with distress, whilst the relationship between objective tinnitus volume, intrusiveness, and severity is less clear and measurement can be challenging (Hall, Mehta, & Fackrell, 2017).

Despite poor correlations between psychophysical characteristics and distress, traditional approaches to tinnitus were biomedical. More recent developments indicate that the tinnitus experience can be better understood using a biopsychosocial model (McKenna, Marks, & Scott, 2018). This aligns with research into other persistent physical symptoms (PPS), where psychosocial factors improve the predictive power of models of physical symptoms. In addition to their physical comorbidity and duration, the severity of PPS is related to anxiety, catastrophic cognitions, embarrassment, avoidance behaviours, and neuroticism (Claassen-van Dessel, van der Wouden, Twisk, Dekker, & van der Horst, 2018). Correspondingly, reductions in symptom severity and distress are associated with changing cognitive and emotional reactions (Marks, Chambers, Russell, & Hunter, 2016). This is relevant to tinnitus, where negative thinking and avoidant coping strategies are associated with severity (Budd & Pugh, 1996; Weise *et al.*, 2013). The cognitive model of tinnitus (McKenna, Handscomb, Hoare, & Hall, 2014) offers biopsychosocial explanation of tinnitus distress maintenance involving negative cognitions, emotions, behaviours, and attention.

These models led to the development of cognitive behavioural therapy (CBT) for tinnitus, for which there is a robust evidence base (Martinez-Devesa, Perera, Theodoulou, & Waddell, 2010). More recently, CBT has been developed to include aspects of meditation and acceptance, in the form of mindfulness-based cognitive therapy (MBCT). MBCT is thought to reduce tinnitus severity by similarly changing cognition, behaviour (particularly avoidance), and emotions, with additional changes to meta-cognition, attention regulation, and acceptance or ‘allowing’ of symptoms, with results showing significant benefits (McKenna, Marks, Hallsworth, & Schaeffe, 2017).

To date, most research is quantitative and focused on measuring variables related to tinnitus severity. Few studies have utilized qualitative methodologies to explore the phenomenology of tinnitus patients from a biopsychosocial perspective. In the broader PPS literature, studies have indicated how social interactions, particularly unclear discussions with health care professionals, are related to negative symptom experience (e.g., Olde Hartman, Hassink-Franke, Lucassen, van Spaendonck, & van Weel, 2009). In contrast, shared decision-making supports more positive consultations within tinnitus clinical encounters (Pryce, Hall, *et al.*, 2018).

Andersson and Edvinsson (2008) utilized grounded theory with seven tinnitus patients, in an attempt to gain a richer picture of the experiences of people with severe tinnitus who had undergone CBT, to support the development of psychological tinnitus theory. Themes included ‘Mixed Feelings about Living with Tinnitus’ (‘consequences’ of tinnitus, ‘treatment experiences’, and ‘tinnitus identity’). This study aims to explore whether similar themes translate from one culture (Sweden) to another (the United Kingdom). It also included patients who had undergone therapy (MBCT), because the authors wished to explore the experience of tinnitus from the perspective of individuals who had developed some psychological awareness of their condition, as this might enable them to see earlier health care experiences with a broader perspective. This study also aimed to develop the earlier study by being more grounded in a biopsychosocial model, by exploring the impact of health care services on tinnitus, and in particular, the type of health care available in the United Kingdom. Interpretative phenomenological analysis (IPA) was chosen as the methodology since it allows the researcher to take a more interpretative approach to the data, from the perspective of a clinician with expertise in biopsychosocial approaches to tinnitus.

Method

Nine individuals were interviewed, and all names have been changed to protect confidentiality. Ages, gender, socio-economic status, and tinnitus duration are shown in Table 1. All had chronic tinnitus that had been severely distressing in the past, and had completed mindfulness-based cognitive therapy (MBCT) at least 6 months prior to interview, as part of a randomized controlled trial (RCT). This time point was chosen pragmatically, as it ensured all quantitative data for the RCT had been gathered. Conducting interviews after treatment completion meant that participants could also reflect on a broader range of experiences with tinnitus than would have been possible before treatment.

Table 1. Overview of participant characteristics

Name	Age	Gender	Tinnitus duration (months)	Initial TQ	Final TQ	Initial CORE-NR	Final CORE-NR
Sarah	59	F	120	40	7 ^a	1.21	0.18 ^a
Kelly	52	F	74	64	47 ^a	2.32	1.68 ^a
Joe	67	M	120	19	12	1.18	0.43 ^a
Adam	58	M	360	58	13 ^a	2.54	1.25 ^a
Matthew	54	M	128	22	14	1.82	0.79 ^a
Peter	64	M	360	36	37	0.54	0.75
Sam	35	M	18	66	39 ^a	2.43	1.75 ^a
James	54	M	36	51	36 ^a	1.25	1.11
Andrew	36	M	204	60	19 ^a	2.57	0.54 ^a

Notes. CORE-NR = Clinical Outcomes in Routine Evaluation Non-Risk Measures; TQ = Tinnitus Questionnaire.

Measures reported here taken just before session 1 and 6-month follow-up.

^aIndicates reliable change has occurred.

Table 1 reports on standardized outcome measures taken before Session 1 of treatment and again 6 months post-treatment. The Tinnitus Questionnaire (TQ; Hallam, 1996), a 41-item self-report measure, assessed tinnitus distress. Total scores are calculated, and reliable and clinically significant change on the TQ requires a change of at least 11 points (McKenna *et al.*, 2017). The Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM) (Evans *et al.*, 2000), a 34-item self-report measure, assessed pan-diagnostic psychological distress. This study reported scores on the CORE-NR (the mean score of the 28 non-risk items in the scale). Reliable change on the CORE is indicated by a reduction of >5 points. Table 1 shows that most participants showed significant improvement on both measures. However, significant improvements were not reported by Peter on either outcome, by Joe and Matthew on the TQ, or by James on the CORE.

Procedure

Six months after completing MBCT, fifteen participants (from two MBCT groups) were invited to take part, nine responded, and all were included. A semi-structured interview was developed using guidelines for IPA (Smith, Larkin, & Flowers, 2009) and consisted of two parts: The part reported here focused on pre-MBCT experiences of tinnitus, and the second part focused on the experience of MBCT (in preparation). Questions were developed after researching previous literature around lived experience of tinnitus and expert discussions with patient groups and tinnitus professionals, and focused on the following areas: when and how tinnitus started, how it affected them, how they coped with it, what treatments they had tried, and what led them to seek psychological help.

Data handling and analysis

Interviews were conducted in a clinical interview room in the hospital where MBCT treatment had been provided. The first author, a clinical psychologist who had delivered MBCT, conducted the interviews, as she had an established working relationship with the interviewees that would support deeper exploration of potentially sensitive topics. She recorded and then transcribed the interviews verbatim. Questions relevant to this analysis asked participants to discuss their experiences of tinnitus and how they coped with it prior to MBCT. Ethical approval was provided by the UK NHS research committee (NCT02059447).

The first author conducted all analysis by hand, in line with the four-stage process of IPA recommended by Smith *et al.* (2009). To support rigorous analysis, each stage conducted by the first author was checked and verified by the second author. Transcripts were read repeatedly, with the first transcript annotated and coded by the first author. This was reviewed and verified by the second author, and this procedure was repeated for a further transcript. Codes were grouped together to form emergent themes for each participant. Themes were cross-analysed across all participants, using thematic mapping of subordinate themes and summary tables. These were checked and amended in an iterative process. From this, superordinate themes were developed that best captured participant experiences, and a master table of themes with supporting extracts was created for the whole group. The master table underpinned the results below, with verbatim extracts used in support of each theme.

Results

Two superordinate themes were identified, 'living with tinnitus' and 'the health care journey', summarized in Table 2.

Living with tinnitus

Tinnitus was challenging, with deep and broad psychosocial effects. It arose unexpectedly and changed with time. Many participants described tinnitus as more than just a 'sound' and reported comorbid symptoms.

James: 'It came on all of a sudden. ... like a thousand birds chirping. ... And then it fluctuated to high and low pitches. ... and from then on it settled down. ... like a jet engine running. ... extremely sharp. ... It's there constantly. ... It gives me headaches. ... I need to cringe my face and shut my eyes tightly to think "oh god that's bad. It's awful."'

Tinnitus development and chronicity

Whether completely new or of increasing severity, tinnitus began suddenly, unexpectedly, and without a clear trigger. This was described as '*shocking*', '*traumatic*', '*terrifying*', and the confusion and inability to cope prompted help-seeking, with a wish to understand and resolve the problem.

Peter: 'My tinnitus started about 30 years ago ... it sort of got a lot worse after quite a long time. ... it was sort of devastating. I was thinking "I've got to live with this loud noise forever."'

In the few cases where a cause was clearly identified (Matthew's tinnitus began after a head injury and hearing loss), participants noted the lack of understanding and '*big black holes in medical knowledge*'. In response, they developed their own narratives to try to make sense of possible causes. For example, one participant underwent a dental procedure, which was followed by an ear infection which may have caused hearing loss. As such, '*the tooth being pulled*' was seen as the cause of tinnitus. His doctors disagreed with this, but could not offer a satisfactory alternative explanation. In the absence of a convincing professional explanations, the lay interpretation of causality was thus based on temporal associations between symptoms. This process becomes problematic if the lay interpretation perpetuates distress, fear, and mistrust in health professionals.

Every participant described the same reaction to tinnitus: negative and catastrophic thoughts about tinnitus and the future, leading to a need to find a '*cure*'. Notably, an absence of cure was equated to further, inevitable deterioration, and not the persistence of their current state. Even Damien, who had previously recovered from severe tinnitus,

Table 2. Master table of themes that emerged from the analysis

Superordinate theme	Subordinate themes
Living with tinnitus	Tinnitus development and chronicity Other symptoms and feeling overwhelmed Isolating and pervasive psychosocial effects
The health care journey	Unhelpful interactions, seeking reassurance, and lack of cure Failed treatments versus helpful health care

was anxious about '*revert(ing) back to*' his severe symptoms. Interactions between tinnitus and cure explored in the second supraordinate theme.

Other symptoms and feeling overwhelmed

Common comorbidities included ear pain, sound sensitivity, balance disorder, hearing loss, headache, and insomnia, and tinnitus tended to be blamed for *causing* these symptoms. However, hearing loss was sometimes diagnosed independently, at which point this was regarded as more significant than tinnitus.

Matthew: '... tinnitus has always sort of gone with the hearing loss... if I hadn't had deafness and I'd just had the tinnitus, then the tinnitus would have affected me more...'

Hearing loss disrupts engagement with the world on several levels (Ramsdell, 1978), including symbolic (understanding language), warning (responding to alarm), and connectedness (feeling 'alive' and connected to ones' environment through sound). Data here indicate that tinnitus too may similarly disrupt engagement with the world, affecting one's fundamental relationship to sound. For example, tinnitus made environmental noises and social interactions difficult to cope with and Kelly described '*finding it hard sometimes to follow conversation*', and how constant noise meant that '*even the most basic things had been spoiled*'. Sam reported how '*relationships seemed to be suffering*' and that he '*couldn't listen to music anymore*' (a particularly important part of his life). Damien felt trapped and dependent on noise-cancelling headphones '*excluding*' himself from the environment.

The dominance of tinnitus was a theme for all interviewees. Tinnitus was '*huge*', '*loud*' (Adam), '*overpowering*' (Sam), an '*invasion of personal space and my ability to be quiet*', '*an enemy*' (Kelly), something that is '*in control of me*' (Sarah). Sam's '*personified*' description of tinnitus indicated a perceived physicality and intentionality, as well as a sound, tinnitus was physically threatening, thus eliciting a fight or flight response.

Sarah: '... It was like being in an orchestra, and fireworks going off at the same time. I would actually feel the noise shooting from one ear to the other... It felt quite painful ... very physical.'

Although externally undetectable, tinnitus occupied emotional, bodily, and attentional space, becoming so overwhelming, it had a '*profound*' effect (James). One reason for this level of interference was related to the fact that tinnitus was located in the head and as such, it impeded basic processes, such as thinking and concentration. For most, the noise was in constant awareness, disturbing their peace, but even when in the background, participants felt drained by tinnitus.

Sam: 'I personally suspect that tinnitus is naturally tiring because it's always there whether you pay attention to it or not... you have to work a bit harder... and you end up tired.'

Respite occurred when tinnitus volume fluctuated or attention shifted onto another task. Although this tended to be momentary and diminished by negative thoughts about tinnitus returning soon, these moments provided individuals with a helpful sense of control, as they knew that engaging in a particular activity could be a reliable coping

mechanism. As Joe described, '*concentrating on something else... made me aware of it less*'.

Isolating and pervasive psychosocial effect

Tinnitus affected physical, psychological, and sociocultural domains, and also interacted with personality traits. Isolation was a prominent theme, exacerbated by the fact that tinnitus is inaudible to others. Unable to fully communicate their particular experience, participants became '*bored*' of complaining about it, as others were unable to offer appropriate empathy since they usually regarded tinnitus to be a mild issue.

Adam: 'Because the general conception still is "oh well, I get that now and then. . . it's not that bad". But it is. It's huge'

Feeling lonely and overwhelmed, participants tried different ways to avoid tinnitus. Sarah illustrated how grave this reaction could become when recounting her '*invasive thoughts*', and at the worst point, she contemplated suicide as the only way to escape the noise. Sarah chose to talk about suicide indirectly, indicating both the pain of this memory and concern about the stigma linked to suicidal ideation. Stigma can hamper open discussion about suicidal thoughts in tinnitus and should be carefully considered when tinnitus patients are very distressed.

Sarah: 'Mentally, it all just felt too much. . . at times I'd have invasive thoughts, you know, quite regularly. It was just too much. I was just too tired and just no reprieve from the noise. . . it was the unseen'.

This sense of stigma attached to tinnitus was apparent elsewhere, as participants indicated through their focus on the physical aspects of tinnitus. Psychological factors were clearly recognized as part of their experience, but the physiological underpinnings of tinnitus needed to be highlighted. Clarity around the fact that tinnitus is a physical condition can help other people to better understand and respect the suffering it can cause.

Sam: '... there is essentially. . . something ringing in my ear, and as far as I am aware tinnitus is not a psychological effect, that it's a real, clinical thing'

Psychological aspects of tinnitus were also important and included cognitive, behavioural, and emotional changes. Negative cognitions tended to be catastrophic ('*it will get worse*', '*I will have to live with this loud noise for ever*'), whilst life without tinnitus – could at times be idealized. For some, tinnitus was seen to exacerbate other difficulties, making it even more threatening and overwhelming.

Damien: '...when I first had it. . . I was quite isolated. . . and a bit depressed . . . so I was kind of worried that I would go back into my shell again'.

Behavioural changes were related to thinking patterns, and individuals spoke about wishing to have help with tinnitus without becoming a burden on others. To reduce the risk of being misunderstood by others, most individuals tried to cope alone by finding ways to *fight* tinnitus. Many used relentless activity as a distraction from the noise and the emotional impact of tinnitus. This could be an effective way of pushing tinnitus '*to the*

side', but it brought other problems such as exhaustion, a lack of peace, and impaired well-being. Sleep was a common problem, and several participants reported insomnia so severe they needed medication.

Sarah: '... it was just that constant, absolute mental exhaustion. It was complete mental exhaustion with no reprieve at night or during the day'.

Distressing emotional changes included anxiety, fear, depression, hopelessness, resignation, loneliness, disconnection, anger, irritation, and devastation. This emotional disturbance fed a vicious cycle of tinnitus distress, and Damien described how tinnitus was an anxiety indicator, '*like a siren's gone off in a building*'.

Social changes arose because participants tended to avoid social interaction or found that interpersonal conflict increased when others were unable to offer full understanding. Hearing difficulties would have aggravated this since communication became generally more stressful. Conversely, participants who had supportive friends or family saw this as crucial to their well-being, for example Damien, credited his partner's encouragement to '*look at different things*' eventually led to effective treatment. A loss of social networks is a critical part of tinnitus impact and risks being overlooked by professionals.

Personality and behavioural tendencies intensified psychosocial changes. Participants whose tinnitus led to social withdrawal recognized a natural tendency to self-isolate, particularly when under stress. Similarly, a propensity to hold oneself to high standards and feel personally responsible for finding solutions affected help-seeking behaviours, and these attitudes meant participants could regard the need to ask for help as a personal weakness. Sarah indicated how tinnitus aggravated long-standing proclivities of social isolation, self-reliance, and catastrophic thinking patterns.

Sarah: 'I tend to isolate myself anyway as a person... but I was completely isolating myself because everything was just too much... I absolutely catastrophize – "I'm going to be homeless the next day" all of that... it's my fault'.

High self-standards were linked to self-blame when an individual could not find a solution for themselves, and they focused on their own failings rather than seeing tinnitus as being related to multiple factors.

Kelly: '...you judge yourself... there's something wrong with you... you are substandard in some way'.

Emotion regulation styles were important, for example Joe's preference to keep emotions '*bottled up*', limited his self-expression ('... *if somehow my emotion's very sad, I wouldn't express it as very sad. Er, I might express it as negative, but not as very sad*'). Similarly, Sarah recognized that earlier (pre-tinnitus) experiences of suicidal ideation probably made her prone to these types of thoughts. Others saw how a personal predisposition to anxiety or depression affected their reaction to tinnitus and other stressors.

Supraordinate theme: The health care journey

The second superordinate theme explored how individuals traversed the health care system. Key experiences involved preoccupation with 'cure' by patients and health care

systems; a vicious cycle of repeated help-seeking provoked by a lack of understanding, treatment failure, and unhelpful consultations; and relief when participants felt properly heard, understood, and helped. Initial forays into health care were biomedically oriented, and psychosocial factors were only explored later on, after multiple consultations.

Unhelpful interactions, seeking reassurance, and lack of cure

Damien: 'There was a tendency to say I don't know where to forward you to. . . so you end up doing a lot of the looking. . . on the internet. . . I was looking too deeply into it and it was making me feel more anxious'.

Although hope was common at first onset, this faded quickly when early appointments did not provide reassurance, understanding, or solutions. All participants wanted clear, causal explanations, assuming this would lead to a cure. For all, 'cure' meant 'silencing' tinnitus, but such a treatment does not yet exist. Unfortunately, the way in which this message was transmitted to participants was usually unhelpful. They were told '*there's nothing that can be done*' or '*you just have to live with it*', suggesting not only that tinnitus will continue, but also that the entire state (the related distress and intrusiveness) would continue too. Such information is in fact inaccurate, and evidence shows that intrusiveness and distress decrease over time as people habituate. Importantly, none of the participants recalled receiving this more hopeful outlook early on, nor were they given advice regarding effective psychosocial and audiological interventions that might have alleviated their distress.

In the absence of clear advice, participants continued their search for help. This included repeated medical 'tests' in the hope that identifying the origin of tinnitus might provide a clear therapeutic target. Yet such tests are rarely conclusive, and the seeking of medical reassurance only exacerbated distress (something commonly seen in health anxiety) and further alienated patients from professionals.

Sam: 'No one has been able to tell me what condition I have. . . I've had lots of test and they didn't tell me what the tests were for. . . (or) explain why I've got a hearing loss, whether there's something broken in my ear. So that added to a general sense of confusion and fractionation'.

The way in which professionals felt about tinnitus was also important. For example, Sarah's sense of futility was intensified by the hopelessness she saw mirrored in her medical team '*I saw a nurse a couple of times, and she was in tears, you know she was really tearful*'. To cope, individuals began to search elsewhere, particularly the Internet, where 'cure' is often promised, but rarely delivered.

These compelling stories show the influence that early health information and communication can have on tinnitus development. It will benefit patients if they feel fully understood by a professional who can offer a compassionate response and convey a realistic sense of hope. Tinnitus affects people differently, and so it should be carefully assessed, allowing an individual 'formulation' of the problem to be created. This in turn can lead to a collaborative approach to choosing care preferences which will empower both clinicians and patients to choose the right treatment plan based on a shared idea of what 'getting better' means.

Instead, these participants were socialized to a 'cure-focused' attitude to tinnitus, and when 'cures' failed, this intensified the difficulties of 'Living with Tinnitus' described above and led to increasing demands for help. As Sarah described, she felt her tinnitus '*was taking me... backwards and forwards, backwards and forwards to the GP*' even though this was not helpful to her. Participants tended to end up relying on their own resources to find help, and in the cases described here, they all eventually found a referral to a specialist tinnitus service (possibly reinforcing beliefs that recovery from tinnitus depends on the self).

Adam: 'The only reason I got onto this course was because I chased... I had to find all this out by myself which was quite annoying and difficult'.

Any physical symptom logically leads people to seek medical treatment, since our prevailing cultural belief about illness is that physical symptoms should respond to physiological treatment (medicine or surgery). Health information about tinnitus perpetuates this belief, even though a biomedical cure does not yet exist, by suggesting that 'nothing can be done'. This message is inaccurate since there are interventions that effectively reduce tinnitus severity. This message is also unhelpful by tacitly suggesting that a 'non-medical' intervention is less credible or desirable than something 'medical', despite the fact that treatments with the best evidence for efficacy are psychosocial and that such therapies are proven to enhance adjustment, acceptance, habituation, and eventual recovery.

Sam: 'I was disappointed... I don't think I'd ruled out a cure. I expected there to be some sort of tangible, physical treatment of the condition, rather than a coping treatment'.

Failed treatments versus helpful health care

As might be expected within a biomedical model, first-line intervention tended to be 'physical' ways of enriching the sound environment (e.g., hearing aids and in-ear maskers). Hearing aids can significantly reduce tinnitus awareness, and when this occurred, they were highly valued. Adam found aids improved his connection to the environment, so tinnitus '*is not the most predominant sound*'. However, this approach was not universally helpful; Matthew found they '*just didn't do anything*', and Peter found his white noise maskers '*... a bit boring to wear and difficult and it didn't really work*'.

As described above, when initial treatments failed, cynicism about health care grew. This had mixed implications for engagement with services later on in the tinnitus journey. By the time, participants were offered mindfulness-based psychological therapy, most were quite sceptical that anything would help them. However, by this point, there was more openness about trying 'alternative' approaches, and many had already trialled various therapies (acupuncture, sacro-cranial osteopathy, Qi Gong, Tai Chi). Scepticism was tempered by willingness to find new ways of living well with tinnitus, and for some, there meant there was less attachment to the idea of a cure.

Damien: 'I'm sceptical about alternative therapies... but I found it quite pleasant experience when I got around the slight weirdness of it...'

Participants noted the benefits of identifying and treating comorbid symptoms (pain, headache, or hearing loss) independently from tinnitus. This allowed tinnitus to be separated from multiple issues (rather than blamed for them). This was helpful since it reduced the sense of being overwhelmed by tinnitus and improved engagement with professionals.

When the 'right' help was offered, it had a significant impact on the experience of tinnitus. The 'right' help included consultation with a clinician who demonstrated professional honesty, kindness, understanding, and validation of their lived experience, who could offer clear explanations and appropriate onward referral. Realistic advice that tinnitus might continue was appreciated ("...*at least the honest doctors said 'well really we just don't know'*") and preferable to a lack of clarity:

Adam: 'I expected something, at least to come out with an understanding, even an explanation or even just to say look, you can't get cured. . . Rather than that, I just remember the guy waffling and going around the subject'.

This supports other research where successful tinnitus counselling involves transparency and good communication. Discussions should shift from the medical view that tinnitus is 'incurable' to an equally accurate but more helpful and encouraging biopsychosocial view that tinnitus can be managed, distress reduced, and habituation facilitated to a point where tinnitus is no longer problematic for people (even if the noise does not stop). This approach could facilitate the adoption of more adaptive responses to tinnitus earlier on, help to engage patients in helpful treatments, and even reduce the development of chronic distress.

Discussion

Tinnitus is a common persistent physical symptom that can begin suddenly and without explanation. The stories here show the ways in which tinnitus can have a profound and extensive impact upon the 1 per cent of adults with severe tinnitus. Such accounts offer valuable insight into the types of difficulties associated with tinnitus and, importantly, what can hinder or facilitate recovery.

In these cases, where tinnitus had been severe, people reported anxiety, depression, insomnia, exhaustion, hopelessness, difficulty in thinking, feeling overwhelmed, and even suicidal thoughts. Tinnitus affected communication, connection with one's environment and other people, and it even affected the sense of self. Other physical difficulties were common (hearing loss and pain particularly). It was regarded as a large, ever-present, inescapable enemy that required ceaseless efforts to cope with, distract from or fight against it.

These experiences of 'living with tinnitus' interacted with the 'health care journey', demonstrating how the tinnitus experience is affected by other people and wider systems, including health care services. Perhaps because of the ubiquity of mild tinnitus, the broad psychosocial impact of severe tinnitus can be easily underestimated, whilst the dominant medical and cure-focused discourse around tinnitus cannot fully account for patient experiences. With no medical cure available, patients would often be told that 'you just have to live with it', and this understandably increased anxiety, hopelessness, and catastrophic thinking, all factors which are known to predict negative outcomes in tinnitus (Cima, Crombez, & Vlaeyen, 2011) and other persistent physical symptoms such as chronic pain (e.g., Turner, Jensen, Warm, & Cardenas, 2002).

These findings underscore the critical role of communication early on in tinnitus, and as seen in other chronic physical conditions (e.g., Smith & Osborn, 2007), psychosocial responses aggravate symptomatology and isolation. Health care services could minimize the development of chronic distress by providing the right information early on. This should involve a biopsychosocial approach offering realistic information and advice on how to move towards recovery and habituation, rather than a medical narrative that indicates a medical 'cure' is desirable, and yet, unavailable. Services should train clinicians who can offer this more holistic approach to tinnitus management, based on collaborative, shared decision-making where a range of options are available (e.g., Pryce, Hall, *et al.*, 2018). Rather than suggesting that 'nothing that can be done', clinicians need to offer the hopeful message that the severity of tinnitus will reduce with time and that this does not depend on finding a cure.

Clinicians could follow good practice in offering evidence-based care options in tinnitus, for example by using the 'Decision Aid' tool (Pryce, Durand, *et al.*, 2018), to support consultations based on honesty, kindness, validation, clear explanation, and appropriate onward referral when indicated. Patients could be given a range of options and collaboratively choose their preference with a clinician. For example:

- (1) *Help patient to understand tinnitus*: Tinnitus is common, not an illness and rarely caused by a medical condition. Hearing loss is sometimes associated, but tinnitus often starts after a change in the ear (e.g., an infection), loud noise exposure, or stressful life events. Medical investigation maybe warranted at first onset, but rarely finds an underlying issue. The tinnitus sound is likely to continue because no treatment currently exists that can 'silence tinnitus'. Successful treatment focuses on *habituation*, which means tinnitus will stop being intrusive and bothersome over time. This often happens automatically and is supported by living a normal life, reducing stress, relaxation, and 'allowing' tinnitus to be present without 'fighting', 'avoiding', or having to 'distract' from it. Professional help can support habituation.
- (2) *Talking Therapies*: Professionals can help to reduce tinnitus-related distress and teach useful skills. Cognitive behavioural therapy, mindfulness-based therapy, and relaxation are indicated and can treat comorbid anxiety, depression, and insomnia.
- (3) *Using Sound*: Background sound (radio, music, sound machines, apps) makes tinnitus less apparent and reduce unhelpful attentional focus and monitoring.
- (4) *Group support*: Groups can reduce the sense of isolation and improve support and understanding of tinnitus.

Currently, this type of approach is not standard in the United Kingdom, and most tinnitus patients do not access services beyond primary care or diagnosis-focused secondary care (McFerran, Hoare, Carr, Ray, & Stockdale, 2018). This leads to 'revolving door' health care: Referral leads to medical investigation, negative investigations lead to discharge, and patients remain distressed, a re-referral ensues. This is an expensive and ineffective pattern and may even cause additional harm by maintaining a biomedical focus and not offering alternative options.

This system is not inevitable. Most tinnitus patients recover when habituation occurs and helpful ways of enhancing this process already exist. Appropriate consultation and assessment can be effective, and positive alliance with a clinician may be even more important than removal of the tinnitus (Pryce, Hall, *et al.*, 2018). More effective early intervention in tinnitus could involve formulation of individual cognitive, behavioural, and attentional mechanisms with proper support and appropriate management strategies. This idea is supported by some evidence that suggests that tinnitus-related distress is

more closely related to cognitive behavioural mechanisms than the acoustic properties of tinnitus (McKenna *et al.*, 2014). Similarly, there is evidence that treatments targeting cognitions, behaviours, and attentional processes (rather than tinnitus itself) can reduce distress and improve quality of life, and mindfulness-based cognitive therapy (McKenna *et al.*, 2017) and cognitive behavioural therapy (Cima *et al.*, 2012) are the most effective. Further research should explore why the biopsychosocial model, although part of medical education, is not evident across routine practice for tinnitus patients in the United Kingdom, and why routine medical practice may struggle to respond to tinnitus patients who are severely troubled.

There are some limitations of this study to consider. Firstly, participants were reflecting on their experiences after completing a course of MBCT, so their reflections were retrospective and refer to their journey up to the point of psychological treatment (the experiences of that particular treatment will be published elsewhere). However, since chronic tinnitus is the subject of this analysis, it necessarily depends on retrospective recall. Taking part in MBCT could have affected participant's reflections on earlier experiences, possibly by making them more aware of cognitive behavioural, and attentional factors affecting distress, and the notion of 'allowing' versus 'fighting' tinnitus. Such insights may not have been so available if interviewed prior to MBCT. Despite this, these data are useful, as participants were able to give insights into their early tinnitus experiences from the perspective of having possibly gained more understanding of the symptom during treatment. This small sample of active help seekers may mean that the findings cannot be generalized to people who cope well with tinnitus, or who, assertively and successfully, seek help early on.

The strength of the study is the depth of insight into what it is like to live with chronic, disabling tinnitus. The IPA approach allowed for an exploration of the biopsychosocial nature of suffering and so offers important understanding about the key issues that drive tinnitus-related distress. These converge with evidence from other literature about the impact of catastrophizing, hopelessness and suicidality on tinnitus, the importance of early intervention, and helpful interactions with professionals. The advantage of the IPA approach is the interpretative nature of the dialogue and analysis, which allows for input from professionals with psychological training and years of experience of working with tinnitus and other PPS using a biopsychosocial model. As such, the interpretation includes additional understanding of this patient group and health care services available to them.

Overall, the experiences of these participants paint a picture of the profound clinical and human impact of tinnitus, and how this may not always be fully understood by others. Reliable, realistic, and accessible information about tinnitus, its causes, consequences, and management are available (for example, the British Tinnitus Association website, local audiology services), and patients should be directed to this early on. Until a 'cure' for the tinnitus noise exists, health care professionals are responsible for ensuring that effective treatment minimizes its impact as soon as possible. There is an urgent need for future research to develop effective ways of improving early clinical interventions that can enhance long-term outcome, so patients with tinnitus can feel hopeful that they can find a way through their suffering.

Conflict of interest

All authors declare no conflict of interest.

Acknowledgements

We would like to thank all participants for giving their time to share their experiences in these interviews. This work was funded and sponsored by the British Tinnitus Association (BTA), and we thank them for their support.

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Received 3 August 2018; revised version received 2 December 2018